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Mindfulness and Autism Spectrum Disorder

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Abstract

The use of mindfulness interventions for individuals with autism spectrum disorder (ASD) is a relatively new research area, which has followed a more established body of research investigating the efficacy of mindfulness interventions for parents of children with ASD. Given the chronic stress levels experienced by parents and high anxiety and stress levels in individuals with ASD, such research is well justified. The utility of mindfulness in clinical practice for individuals with ASD and their parents will be discussed. This chapter aims to evaluate the research literature, identify important limitations, and propose crucial directions for future research. Acknowledgment of the impact of attitudes, social bias, and a generational shift that may be accelerating the salience of mindfulness is discussed. The author aims to emphasize the importance of high-quality future research with robust methodological designs to clearly identify the potential role for mindfulness in this population. Despite having a solid foundation of *preliminary* findings, it is important that researchers refine current procedures and evaluation of mindfulness interventions for individuals with ASD and their parents while carefully selecting measures that are not solely self-report or parent report.

Keywords: autism, mindfulness, meditation, stress, parenting

1. Introduction

The adverse role of stress, fear, and anxiety in individuals with autism spectrum disorder (ASD) was identified in Kanner's [1] first description of autism in his pioneering paper *Autistic Disturbances of Affective Contact*. The implications of stress and anxiety in individuals with ASD have been investigated over decades, yet we are still analyzing their detrimental impact on the developmental trajectory and mental health of individuals with ASD [2–4]. Psychological stress occurs when an individual perceives that environmental demands tax or exceed his or her

adaptive capacity [5]. While stress is a universal human experience, which can be helpful at times, prolonged or chronic elevated stress levels are detrimental to an individual's health and well-being [6]. In contrast, anxiety is an emotion characterized by an unpleasant state of uneasiness and worry, which is often accompanied by nervous behavior, and has the potential to result in a clinical anxiety disorder [7–9]. Chronic stress and anxiety are experienced by many individuals with ASD, however, have also been consistently associated with parenting a child with ASD [10–12]. There is preliminary evidence to suggest that mindfulness training reduces stress and results in a myriad of positive changes in individuals with ASD and their parents. This chapter will review the literature and aim to analyze the participants, methodologies, interventions, and research designs across the body of work in order to determine the robustness of the findings. The implications for the clinical application and directions for the future research on mindfulness interventions for individuals with ASD and their parents will be discussed.

2. Discussion

2.1. Autism, stress and anxiety

The detrimental role of stress and anxiety experienced by individuals with ASD has been investigated over decades. Kanner proposed that “the child's behavior is governed by an anxiously obsessive desire for the maintenance of sameness” ([1], p. 245), and a number of early researchers argued that the core features of behavior of those with ASD, engagement in obsession and stereotypical and repetitive behavior, were a function of managing anxiety and distress [13–15]. Similarly, more recent research has found that the level of anxiety in adults with ASD is three times higher than adults with intellectual disability [16]. This study found that the higher the anxiety and stress levels in the adults with ASD, the less likely they were able to cope with change, sensory stimuli, and what they perceived to be unpleasant events.

A literature review conducted by MacNeil et al. [17] found that adolescents with ASD experience greater levels of anxiety than the general community population. Such levels were similar to those with clinically significant levels of anxiety, however, often presented different patterns of anxiety compared to other clinical groups. Previous research has attributed symptoms of social anxiety in adolescents with ASD to factors including social skill deficits and heightened physiological arousal [18]. Similar to the role of anxiety in adults as described by Kanner [1] and Gillott and Standen [16], Wood and Gadow [19] suggest that anxiety may play three roles for adolescents with ASD: (1) a downstream consequence of ASD symptoms (e.g., via stress generation through social rejection), (2) a moderator of ASD symptom severity, such that certain core autism symptoms like social skill deficits and repetitive behaviors may be exacerbated by anxiety, and (3) a proxy of core ASD symptoms. A noteworthy finding and reoccurring theme across the literature that discusses the prevalence of anxiety in adolescents with ASD is that regardless of how it is measured, anxiety is common in children and adolescents with ASD, despite not always displaying age-typical symptoms [4].

Children with ASD also display high anxiety levels, particularly on measures that identify traits of separation anxiety and obsessive-compulsive disorder [20]. In a study that recorded

cortisol levels as a measure of stress in children with ASD, increased cortisol was observed following exposure to a novel, nonsocial stimulus [21]. Thus, the desire for sameness and avoidance of novel stimuli may play a role in symptoms of stress and anxiety in children with ASD, which appears to remain high and potentially increase in adolescence and adulthood. The increase in stress and anxiety from adolescence to adulthood may also be moderated by poor social skills and social rejection. This is detrimental to the development and quality of life for individuals with ASD across the trajectory of their life span. It is essential that interventions successfully target these symptoms in order to maximize the developmental potential and quality of life for individuals with ASD.

2.2. Autism and parent stress

Over time, researchers have consistently shown that parenting a child with ASD is associated with a multitude of challenges and daily stressors. More recently, researchers have also found that parents of children with ASD experience higher stress levels, in addition to symptoms of anxiety and depression when compared to parents of typically developing children and parents of children with other disabilities including Down syndrome, behavioral disorders, and fragile X syndrome [10, 22–25]. Early research reports from the 1970s indicated that parents of children with ASD have a reduced quality of life, high parental burnout, and regular feelings of isolation [12]. In 1984, a book titled *The Effects of Autism on the Family* discussed the issue of parent stress on the family system throughout the manuscript [26]. Marcus [27] proposed that the “unrelieved care” of raising a child with ASD appears foremost among parent stressors. Marcus [27] and Sullivan et al. [12] acknowledged that the severity and long-withstanding nature of ASD, in parallel with the lack of available and appropriate resources, is a key driver of parent stress. Other factors that Marcus [27] proposed that contribute to the physical and emotional exhaustion and parental burnout include difficulties in obtaining a proper diagnosis and appropriate supportive services, pervasive loneliness, and isolation due to raising a child with high needs, inadequate supportive services, and neglect of personal, social, and medical needs of parents. Despite this research being published 32 years ago and the significant advancements in the field of psychological intervention over the last three decades, similar, if not identical, issues potentially still mediate stress levels and burnout in parents of children with ASD today.

The age of receiving an ASD diagnosis is reducing due to increases in early screening and improved diagnostic tools [28–30]. However, parents still report that receiving a diagnosis can be a difficult and stressful experience [31]. Once a child receives a diagnosis of ASD, parents may experience a myriad of negative emotions characterized by guilt, blame, and fear [32]. Many parents also report feelings of grief and loss as they adjust to not having a typically developing child [33]. Such emotions, coupled with high levels of stress, anxiety, and depressive symptoms, result in these parents being psychologically vulnerable. At the same time, parents may be managing conflict and challenging behavior with their child, dealing with problems at childcare centers or schools, caregiving for other children, keeping their household functioning, working, and coping with financial stressors. There is no cure for ASD, and it is considered a lifelong condition; however, parents are likely to seek a treatment to alleviate

symptoms in their child. Thus, at this time of heightened stress, parents are exposed to conflicting treatment information and are responsible for selecting the best intervention and treatment approach for their child, which is likely to result in further distress. Due to misleading information, parents often partake in treatments that lack empirical support [34]. To this end, there is often financial strain on parents when they are trialing and maintaining treatment approaches. Due to the multitude of factors described, parents of children with ASD are among the most stressed and at-risk parents in society; however, there are limited evidence-based procedures designed to address such issues.

2.3. What is mindfulness?

Mindfulness can be simply defined as paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally [35]. Known as the “father of mindfulness” in the Western world, Kabat-Zinn [35] proposes that mindfulness aims to cultivate nonjudgmental and nonreactive attention to experiences in the present moment, including our body sensations, cognitions, emotions, and urges. Mindfulness is an ancient Buddhist practice, however, has profound relevance to modern psychology. Hassed and Chambers ([36], p. 6) propose that mindfulness is “a mental discipline aimed at training attention,” and they quoted a classic textbook in psychology by William James ([37], p. 5), whereby James proposed that “the faculty of voluntarily bringing back a wandering attention over and over again, is the very root of judgment, character and will.” The notion of training attention is not a new phenomenon in psychology.

Mindfulness constitutes formal practice, known as mindfulness meditation, and informal practice, which involves our sensory experiences, moment to moment, in everyday life. Kabat-Zinn [38] outlines that the purposeful control of attention, of that we refer to as mindfulness, can be learned through meditation. Mindfulness meditation is commonly referred to as a state that can become a mental position that facilitates the ability to disengage a given experience from an associated emotion, resulting in a mindful or skillful response to a situation [39, 40]. Seemingly simple, however not necessarily easy to achieve. Further, it requires effort and discipline as it works against our habitual awareness and automaticity [41]. Gunaratana [42] rightfully suggests that mindfulness cannot be entirely captured with words because it is a subtle, nonverbal experience.

The term mindfulness or meditation may provoke attitudes or preexisting assumptions that may be inaccurate. While many individuals may consider mindfulness a spiritual endeavor or a religious practice, it is vital that we are critical and rigorous in evaluating the psychological literature and base our opinions on a foundation of evidence-based research that consists of robust methodologies and accuracy in reporting results. Mindfulness-based stress reduction (MBSR) programs have been found to be effective in resulting in positive change and are being utilized in clinical practice in a wide variety of clinical populations. Keng et al. [43] conducted a comprehensive empirical review of 16 randomized control trials (RCTs) that implemented an MBSR program among both clinical and nonclinical populations. They found a reduction in symptoms of psychological distress, anxiety, depression, anger, rumination, cognitive disorganization, posttraumatic avoidance symptoms and medical symptoms. Keng and

colleagues [43] also proposed a myriad of significant positive effects of the MBSR program including an improvement in positive affect, a sense of spirituality, empathy, a sense of cohesion, mindfulness, forgiveness, self-compassion, satisfaction with life, and quality of life. The 16 RCTs included in this review consisted of participants that were students, community adults, professionals, cancer patients, fibromyalgia patients, generalized social anxiety disorder patients, adults with high stress, and patients with multiple sclerosis, which highlights the versatility of mindfulness-based interventions [43].

The feasibility of utilizing mindfulness training as a sustainable, time-effective, and cost-effective tool for individuals caring with others with disabilities is gaining increased academic attention. A leading research team in the field of mindfulness and developmental disabilities recently conducted a benefit-cost analysis of implementing a mindfulness-based positive behavior support (MBPBS) training program to staff of community group homes for individuals with developmental disabilities [44]. Outcome measures included the frequency of verbal redirection and physical restraint, staff stress levels, and turnover, in addition to staff and peer injuries. They found significant reductions in the use of verbal redirection, complete disuse of physical restraints within a few weeks of MBPBS training, and cessation of staff and peer injuries. In addition to substantial financial savings due to staff participation in the program, results showed a significant reduction in staff stress, and there was no staff turnover during this program. Such findings are important to replicate in parents of children with ASD which may be further extended to caring staff and teachers, in terms of conducting a cost-benefit analysis.

2.4. What is mindful parenting?

Mindful parenting brings the elements of mindfulness to parenting, first described by Kabat-Zinn and Kabat-Zinn ([45], p. 71) as paying attention to your child and your parenting in a particular way: intentionally, here and now, and nonjudgmentally which “calls to wake up to the possibilities, the benefits, and the challenges of parenting with a new awareness and intentionality.” A more recent definition by the pioneer of mindful parenting refers to “the awareness that emerges through paying attention, on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” ([46], p. 145). Experts have long argued that mindful parenting is a fundamental parenting skill [45, 47]. When compared with traditional forms of mindfulness, mindful parenting is a relatively new phenomenon which has demonstrated an increase in both research and awareness recently regarding its efficacy in clinical and nonclinical populations.

Mindful parenting programs were developed to reduce parenting stress; however, recent research has found a myriad of positive outcomes in parents that utilize mindfulness in interactions with their children [48, 49]. A literature review by Bögels et al. [48] proposed that mindful parenting improved parent-child interactions in mental health settings which was characterized by changes in parents including increased attention, reduced stress and preoccupation, improved executive functioning, breaking the cycle of repeating dysfunctional schemes from their own upbringing, and increasing self-nourishing attention. Research conducted by the same research team found that mindful parenting training resulted in an

improvement in parenting, parental stress and reactivity to stressors, parental experiential avoidance, parent and child behavior and emotional problems, and general mindfulness in parents, in addition to improvements in the process of co-parenting and marital functioning [48, 50, 51]. Furthermore, mindful parenting may be essential in promoting positive relationships and psychological well-being in parents and their children.

2.5. Mindful parenting and autism

Based on the research of Sameroff [52, 53], Singh and colleagues [54] outlined that transactional analysis indicates that parents and children are active participants in the development of the children, including their problem behaviors. Therefore, utilizing tools to teach parents to reduce their stress levels in order to alter parent-child transactions that may impact the development or maintenance of problem behaviors in their children is warranted [54]. Given parenting a child with ASD has been consistently correlated with high levels of stress, depression, anxiety, and reduced quality of life due to the ongoing nature of care [10, 22, 55], researchers such as Singh and colleagues [54] have investigated the efficacy of mindful parenting in this population.

A recent systematic review conducted by the current author and her colleagues investigated the impact of mindfulness interventions in parents of children with ASD across ten studies [56]. All 10 included studies contributed at least one self-report finding supporting the effectiveness of mindfulness interventions in reducing stress and increasing psychological well-being in parents. Seven studies that measured parental stress as a primary variable found decreased levels on self-report measures in parents of children with ASD associated with mindfulness training [44, 57–62]. Three studies reported that their physiological findings, which included measures of cortisol levels and galvanic skin response, signified reduced stress levels and emotional responses [62–64]. In addition, four studies found decreased self-reported depression post-mindfulness training [58, 59, 63, 64]. Across the 10 included studies, many improvements related to broad psychological well-being were noted, including reductions in overall health complaints, mood disturbances, and self-reported somatic symptoms. An increase in self-perceived general health, greater satisfaction with their parenting skills, and increased mindfulness and quality of life in parents were also reported.

In the same systematic review [56], two longitudinal studies presented alluring findings that extend the potential of mindful parenting programs, reporting a positive indirect ripple effect of parental mindfulness training in reducing aggressive behavior and increasing compliance in their children with ASD, with effects lasting up to 12 months [44, 54]. The authors reported that following mindfulness training, these children were engaging in very little, if any, aggressive behavior. This review provides preliminary evidence that mindful parenting interventions may be effective in enhancing positive outcomes in parents of children with ASD, and in turn, these results have the potential to trigger a positive ripple effect to their children and promote healthy behavior.

Surprisingly, eight studies utilized broad mindfulness programs, and only two studies, de Bruin and colleagues [57] and Singh and colleagues [54], utilized specific mindful parenting programs. The mindfulness interventions resulted in positive changes in parents; however, the

development of a mindful parenting program specific to parenting ASD or further evaluating the effectiveness and efficacy of current programs may be essential.

2.6. Mindfulness in individuals with autism

Research evaluating the effectiveness of mindfulness interventions in individuals with ASD is very new and is significantly behind the mindfulness research literature in other populations. This may be surprising among clinicians who provide counseling and cognitive therapy to individuals with ASD. The most recent systematic review conducted by the current author and her colleagues identified only six studies and investigated the efficacy of mindfulness interventions in reducing stress, anxiety, depression, rumination, aggression, and increasing positive affect and psychological well-being in individuals with ASD [65]. The participants ranged in the studies from children and adolescents to high-functioning adults. A quality assessment rated three studies as weak, one as adequate and two as strong in research design strength. One study measured the effects of mindfulness in children and their parents. In contrast, three studies investigated outcomes in adolescents and two in adults with high-functioning ASD. The findings of this review will be examined in further detail.

Results of one study indicated that an 8-week mindfulness program, followed by 12 months of mindfulness training, led to an increase in the quality of family life, a reduction in stress in parents, and a reduction in anxiety and thought problems in children with ASD [66]. The effects were cumulative throughout the 12 months of practice. While this result is positive, it is largely based on self-report measures of child behavior and parent stress. A good preliminary finding, however, replication and refinement of direct observational data collection in future research, is essential. Similarly, de Bruin and colleagues [57] conducted a mindfulness program designed specifically to help adolescents cope with common stressors associated with ASD in parallel to the mindful parenting program. This study found a significant increase in quality of life which remained at follow-up and a significant decrease in rumination from pretest to follow-up [57]. Parents also reported that their children's social responsiveness significantly improved at follow-up, in addition to social cognition, social communication, and reduced preoccupations at posttest. The authors proposed that these results may represent improvements in the adolescents' theory of mind, central coherence, and executive functioning. While these findings are an important step forward in investigating the impact of mindfulness in developing social awareness and cognition in adolescents with ASD, this study is also reliant on self-report measures of such variables. In order to validate the proposed positive impacts of mindfulness training as reported by Hwang and colleagues [66] and de Bruin and colleagues [57], future research must move away from solely utilizing self-report or parent-report measures of behavior and develop superior methodological designs that potentially include mixed methods such as structured measures of direct behavioral observation and physiological changes that may be complimented by self-report measures. In consideration of parent-report measures, utilizing either parents or siblings to calculate interobserver agreement (IOA) may be beneficial.

A research team based in the United States led by Singh published several studies that found mindfulness to be effective in reducing aggression, resulting in positive changes in individuals

with a range of conditions including intellectual disability, conduct disorder, mental illness, and Prader-Willi syndrome [67–70]. More recently, this research team turned their attention to investigating the effectiveness of Singh's "Soles of the Feet Program" for adolescents with ASD [71, 72]. One parent recorded incidents of aggression, whereby another family member also recorded incidents 30% of the time in order to determine IOA. In one study, the adolescents' incidents of aggression reduced significantly, with no instances observed during the last 3 weeks of mindfulness practice and with no episodes of physical aggression occurring within a 4-year follow-up [71]. The other study also found that incidents of aggression reduced significantly, whereby aggression occurred at a rate of about once per year during a 3-year follow-up period [72].

Two recent studies investigated the psychological effects of a mindfulness intervention in adults with ASD with an average to high intellectual quotient (IQ) and verbal ability (VA) [73, 74]. Kiep and colleagues [73] adopted a within-group pre- and post-comparison design, whereby they reported improvements in symptoms of anxiety, depression, agoraphobia, somatization, inadequacy in thinking and eating, distrust and interpersonal sensitivity, sleeping problems, general psychological and physical well-being, and rumination during the intervention phase. The decline in rumination was related to the effect of the intervention on symptoms of depression both during and after the intervention and to symptoms of anxiety post intervention. They also proposed that participants displayed an increase in positive affect while hostility did not change. Although no differences were found between self-reported symptoms from baseline to 9 weeks after treatment, the authors suggested that this represented stable treatment results over time. In contrast, Spek and colleagues [74] conducted an RCT, and despite being considered the gold standard research design, this was a unique design among this research literature. The authors proposed that there was a reduction in symptoms of anxiety, depression, and rumination in the intervention group that was not present in the control group of adults. In addition, positive affect increased in the intervention group as opposed to the control group. These studies are pivotal in promoting future research in using mindfulness in adults with ASD. When interpreting such results, it is important to consider that these two studies were conducted by the same research team. In summary, they reported a reduction of symptoms based on self-report measures which are, however, only representative of adults with an average or high IQ and VA, otherwise often referred to as high-functioning ASD.

2.7. Future research and directions

The rapid propagation of the awareness and use of mindfulness in clinical and nonclinical practice, in addition to the research literature, may be indicative of a socially accepted phenomenon that is potentially influenced at a generational level. Due to the wide acceptance and increasingly prevalent discussion around mindfulness meditation in academic and nonacademic literature, the language is becoming more salient. This is potentially influenced by the expeditious development of websites, resources, mobile applications, and awareness on social media platforms, which may be creating a social bias. While a common saying is that "the research is finally catching up to the practice," we must carefully communicate the robust

empirical support, particularly when we are working with high-risk, clinical populations. As previously mentioned, parents of children with ASD already face difficult decisions relating to optimal treatment choice for their child and family; therefore, it is important that researchers and practitioners commit to scientific integrity and evidence-based practice.

At this point in time, there are solid *preliminary* findings to suggest that mindfulness-based interventions may result in effective positive change in individuals with ASD. As discussed throughout this chapter, the body of research is currently inconclusive, despite having a general positive trend in results across studies. A major limitation is that there is an overrepresentation and reliance on self-report and parent-report questionnaires as a measure of stress, anxiety, parent-child interactions, quality of life, social responsiveness, and behavior. While this validates the need for future research to take superior precision in choice of measures, it does not constitute empirical support to conclude that mindfulness is effective in creating such change in individuals with ASD. Secondly, the research is scarce when investigating each age group individually, from children to adolescence and adulthood. Future research should investigate each stage of the life span to clarify the impact of mindfulness practice on each age group specifically. There is also minimal evidence on using mindfulness for individuals that are considered have low-functioning or nonverbal ASD. Such contrasts are important to make for the future application of mindfulness in this population. The evidence base for using mindfulness as an intervention to *parents* of children with ASD is more developed. This research has consistently shown reduced stressed, anxiety, depressive symptoms, and a range of improvements in broad psychological well-being. However, this body of research consists of studies that utilize mostly self-report measures of psychological stress, symptoms, and well-being. Likewise, future research should aim to design more robust designs by including a variety of measures including structured observations and physiological findings, in addition to parent report. As four studies in our review [65] utilized an acceptance and commitment therapy (ACT) intervention which is based on the principles of mindfulness, future research should contrast if ACT is superior to sole mindfulness interventions.

In summary, it is essential that future research refines current methodological issues, adopts high-quality measures of treatment fidelity, and includes a range of valid data collection measures across participants of different ages and levels of functioning to add meaningful research to the current evidence base. It will be beneficial to include an economic evaluation of implementing mindfulness interventions for individuals with ASD and their parents in order to determine the cost-effectiveness. Future research should investigate how mindfulness may compliment and advance current evidence-based treatments in reducing symptoms for individuals with ASD, such as applied behavior analysis (ABA)-based early intervention and cognitive behavior therapy (CBT) [75, 76]. As mindfulness generally does not teach explicit developmental skills, it may be most effective in reducing stress and increasing psychological well-being in individuals with ASD and therefore indirectly increase their skill acquisition and ability to develop cognition while engaging in other interventions. The role of mindfulness in individuals with ASD may be pivotal; however, further clarification of the clinical utility of mindfulness in best practice is required.

3. Conclusions

The use of mindfulness interventions in individuals with ASD is a relatively recent research area, which has followed the more established body of research investigating the efficacy of mindfulness interventions for parents of children with ASD. Given the chronic stress endured in parents, in addition to high anxiety and stress levels in individuals with ASD, such research is well justified. The two systematic reviews discussed in this chapter encapsulate the existing body of research evaluating the efficacy of mindfulness interventions in individuals with ASD and their parents [56, 65]. It can be concluded that mindfulness interventions may be considered an evidence-based intervention in parents of children with ASD; however, additional research is required in order to be considered as evidence-based practice in individuals with ASD. That point notwithstanding the positive and promising results that have been presented. As proposed in our review [65], it is essential that researchers continue to refine mindfulness-based intervention procedures and their evaluation, aimed at maximizing the efficacy of current interventions available for individuals with ASD and their parents.

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